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MYELOMENINGOCELE—PART IV

Psychosocial Problems and Social Work Interventions

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THE PSYCHOSOCIAL PROBLEMS resulting from a diagnosis of spina bifida can be enormous for the child and his or her family and have the potential for interfering greatly with a reasonably normal life for both. In most cases stresses are directly related to the multiplicity and severity of the medical problems with which each child is affected. Other contributors to this symposium emphasize the need for immediate involvement with the family by a team of experts. I shall discuss the problems that arise after the initial period of trauma and continue thereafter and the social work interventions that enable the child and family to cope with the problems.

The following psychosocial problems may be anticipated:

- Financial strain on the family budget
- Physical and emotional strain on the chief caretaker, usually the mother
- Social isolation of parents and child
- Difficult decisions and feelings related to family planning
- Anxiety accompanying a variety of ongoing medical and surgical procedures
- Inability of parents to allow child maximal independence
- Emotional trauma to parents and child when the child must be placed outside the home
- Problems due to bowel and bladder incontinence, particularly when the child is away from home
- Anxieties about sexual functioning

- Child's poor self-image and concern about physical appearance
- Generalized worry about the future

Social work services fall into three major areas: referral to and follow-up with community agencies, casework with child and family, and communication.

Medical costs can be enormous and may continue for many years, so parents need information as to what financial resources are available, and they may need emotional and concrete assistance in doing what is required to obtain financial support. A public health nurse is a valuable asset to the family and the clinic team in providing continuity of care as well as teaching and supervising the care given by the mother. For instance, parents do not always understand the techniques or importance of emptying a child's bladder. Most children with spina bifida attend schools for the orthopedically handicapped and the social worker acts as liaison with school staffs when necessary. A referral to a sheltered workshop or the department of rehabilitation is indicated for some older teenagers. Occasionally there is a need for parents to have more intensive counseling than can be given by the social worker during clinic visits and a referral is made for family or marriage counseling. If a child is placed outside the home, the child welfare services worker and caretaker will need information about spina bifida and the psychosocial problems the child has both manifested and encountered. Joe, 14, was placed in a residential treatment center because the family could not cope with his disabilities, particularly incontinence. The staff at the center, through lack of information, reacted to him much as his family had and he began to repeat unacceptable behavior until the social worker provided the staff with an understanding of Joe's problems.

During clinic visits, the social worker provides casework to parents and child. She evaluates the emotional, physical and financial ability of the parents to carry out recommendations and to provide necessary care at any given time. Alice's family was shaky but gave her adequate care until she was nine, when it became obvious that conflicts within the family, compounded by Alice's medical problems, made it impossible for the parents to care for her adequately any longer. Casework enabled parents to make a decision to place their child in a foster home and Alice began to adjust to the change.

Part IV of an article in six parts.

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Parents require ongoing supportive casework to cope with long-term responsibility and care, to make decisions repeatedly about hospitalization and procedures. They need encouragement to maintain social activities away from the child and to ask for and find resources for relief from 24-hour care. Fifteen-year-old Ted had massive orthopedic involvement. His mother was a single parent who until his first clinic visit had hardly left the house for several years. Parents are greatly in need of genetic counseling to resolve feelings of guilt which are often present and to fully understand the risk of recurrence of spina bifida in future children.

The social worker may have to emphasize over and over the value in a child's being as independent as possible. Two years went by before ten-year-old Mary's mother reached a point where she could allow Mary to change her own diapers. The older child who presents a physically normal appearance but lacks bowel and bladder control needs not only adequate devices and instruction in self-care but help in accepting and living with this problem. The focus of casework is on developing an optimal self-image. It was only when Jane, 13, began to feel some sense of self-worth that she was ready to keep herself clean enough to eliminate the odor of urine which had made her open to ridicule and social isolation.

Psychosexual counseling is crucial for teenagers and parents. The older the child, the more specific the information he or she must be given. To provide this type of counseling the social worker has to be well informed and comfortable in dealing with the subject. Tom, 18, who wore a catheter, was starting college without ever having dated and had decided he would never marry. In one clinic visit with the social worker he began to see the possibilities open to him for achieving an adequate sexual relationship and to approach the subject of his psychosexual functioning from a different viewpoint.

The social worker is an important link in the chain of communication between child and family and clinic team. She informs the team of psychosocial problems which interfere with treatment or make it unrealistic to expect that recommendations will be carried out. Paul was confined to a wheelchair and was obese. The team repeatedly urged his mother to put him on a diet (which she did not do) until the social worker pointed out that the whole family was obese and not apt to change their eating habits. The social worker is

sometimes the only member of the team who knows all the questions the child or family has, so she makes sure that questions are asked and answers are understood. She is usually the liaison who keeps communication open between clinic team and community agencies. The importance of her role in maintaining the flow of communication in all directions cannot be overemphasized.

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MYELOMENINGOCELE—PART V

Neurosurgical Aspects

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THE PROBLEMS of myelomeningocele and meningocele are those of spinal dysraphism. These are not isolated defects, but rather conditions that involve the entire motor system. The ventricles and the circulation of the spinal fluid, as well as the spinal cord and its coverings, are involved. The meningocele that one observes is actually an outline of the meninges protruding through a bony defect; it has spinal fluid in it and occasionally it will also have some fat but it has no nerve tissue, this absence being basic to the definition of a meningocele—that is, the cord and the nerve roots are intact and are not involved in the defect.

A more serious lesion, that of meningomyelocele, or what we now prefer to call myelomeningocele, putting the cord part first, always involves the spinal cord as a part of the defect. There may be displacement of the cord, duplication of the cord, or separation of it, often in the lumbosacral region, and there will be tethering of roots in the dome of the defect with a consequent neurological deficit. We have found the ratio of myelomeningocele to simple meningocele to be about eight to one. There are also more rare and complicated forms of rachischisis in which the cord is displaced into

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